

Providing Access to Community Archives within Government Archives

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ABSTRACT

Problem statement: Since 2010 I have been part of the Central State Hospital Digital Library and Archives Project to digitize records from the first state psychiatric hospital for African-Americans, founded in 1870 in Virginia at the instance of the Freedman's Bureau and run by the state. Many of the records not yet accessioned by the Library of Virginia have been digitized and we are now working on a set of tools for lawful access, including one that can be used for automated redaction to protect sensitive data and suit the needs of different stakeholder groups.

Findings: We were especially concerned about the communities that have grown up around psychiatric hospitals. Discussions among archivists in the past 10-15 years about community archives have made it clear that communities are very much interested in being treated fairly with reference to records kept by others about them and held by archives, while historians and medical researchers have different concerns. According to HIPAA, medical records can be opened after at least 50 years, or longer if the state requires it. We decided to ask especially about whether archives would even be interested in redaction for this application, which might make it possible to limit access to specific stakeholders, and found our respondents nearly unanimous. The proposed presentation will address this issue and the details of findings.

DRAMATIS PERSONAE

The Central State Hospital records reflect the activities of a group of communities that has grown and evolved with the passing of time.

From the start there have been **physicians**, some of whom were involved in the management of the hospital. There have also been **nursing/care staff**, who had been especially responsible for the recordkeeping that provides patient records. During the earliest period of the hospital, **families** were responsible for the presence of the patient in the hospital and were given some control over them. The **patients** themselves apparently enjoyed differing degrees of freedom based on the current theory of treatment, but were comparatively circumscribed in their ability to control their own treatment. Finally, in more modern times some patients were housed in the hospital for "forensic" reasons: they were adjudged criminally insane and were sent to the hospital by the course of criminal justice.

Among these groups only one transcends the passage of time: the **families**, for whom concern for the patients—and concern possibly for the patients' reflection on the families themselves—has been continuous and has become more important as general education has improved and the desire to understand not only family relationships but also genetic issues around the family have increased.

At the same time, a new group, **historical and anthropological scholars**, have begun to investigate hospitals like Central State for their history, the evolution of their treatments, and an understanding of the evolution of concepts around the idea of mental disease or disturbance. And with the evolution of the notion of "archives power," **archivists** themselves have begun to voice concern about how such records should ethically be used.

OBJECTIVES

My concern in this portion of the research was to discover what the **archival stance** was with relation to legal access to the patient records of the hospital. I hoped to find in archivists' responses to the questions how concerned they were to **serve the stakeholders** discussed above: patients and their families; hospital employees including doctors, nurses, and administrative staff; and researchers of various kinds. I also wanted to discover whether the growing interest in the archival field in **community archives**, and even the understanding of the hospital as a congeries of communities, might manifest itself in a changed focus of consideration of a **varied release of hospital records**.

METHODS

Methodology: We used a Qualtrics questionnaire to gather data about sensitive records and sent it to all the states. We achieved a relatively good spread across the US, with responses from 19 states representing just under half the population of the country. The questionnaire focused among other things on the concerns of the people by whom and about whom the records were made, responding to the current concern in the archival world for ethical treatment of the communities around psychiatric hospitals. This concern meant that we would be especially focused on the abilities of our tools to constrain access where appropriate and where needed by archives to comply both with the law and with the wishes of directly-involved communities.

RESULTS

- Kinds of restrictions on the sharing of patient data
 - Institutional Policy (8)
 - Requirements of the deed of gift (7)
 - Incomplete processing (7)
 - Legal issues (16)
 - Other (3)
- Whether digital redaction might permit the archive to offer better service to stakeholders
 - Yes (16)
 - No (2)
- Stakeholder populations seen by state archives
 - Academic/scholarly (18)
 - Teachers (14)
 - Genealogists (17)
 - Government employees (18)
 - Patrons with professional needs (17)
 - Other (7)
- Likelihood of access for designated stakeholder populations
 - Yes (12)
 - No (6)

DISCUSSION

In the new century, as archivists have begun to confront the fact that once one recognizes that others than governments and famous people produce records that are significant for our understanding of our world, many have also come to the conclusion, along with Terry Cook (2013), that the new-century archivist may become a facilitator of the preservation of tradition and the past in gathering in archival materials that may not be immediately shareable.

Individual hospital records mark the extreme case of this problem, since in spite of the use of individual records for medical research, there are still no rules or even "best practices" that go beyond an assertion that patients' privacy should be respected: even studies done on the subject still are only concerned with whether researchers can protect their data long enough to profit by them, whether in terms of academic rank or actual monetary profit (Bull, 2015).

Clearly the benefits of medical research are easier for people in general to understand than, for example, the historian's efforts to paint a portrait of the formation of groups of people with different experiences of a hospital and the sociologist's analysis of how the healing to be had there is shaped or may vary from place to place and culture to culture (Mol, 2003). Current efforts to preserve historical medical records as we have been doing in our project may lead to more efforts to understand them by historians, social scientists, and information scientists; with more work with stakeholder groups whose identities are tied up in these records, both medical research and the communities themselves may find the rewards they deserve (Jimerson, 2009).

CONCLUSIONS

- Archives we surveyed were interested in considering how to work within legal restrictions on the sharing of patient data.
- Archives were interested in the possibilities of using digital redaction so as to offer better service by making redacted materials available to researchers.
- Archives were relatively in agreement on what stakeholder populations they had.
- The majority of archives were interested in according varied access to stakeholder groups given the nature of the groups' relation to the data to be shared.

The Central State Hospital Digital Library and Archives Project thanks the Andrew W. Mellon Foundation for funding for this project.